

University of Groningen

Towards a person-centred approach for older people with intellectual disabilities

Schaap, Feija

DOI:
[10.33612/diss.102982781](https://doi.org/10.33612/diss.102982781)

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2019

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Schaap, F. (2019). *Towards a person-centred approach for older people with intellectual disabilities: the use and effect of Dementia Care Mapping*. [Thesis fully internal (DIV), University of Groningen]. University of Groningen. <https://doi.org/10.33612/diss.102982781>

Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

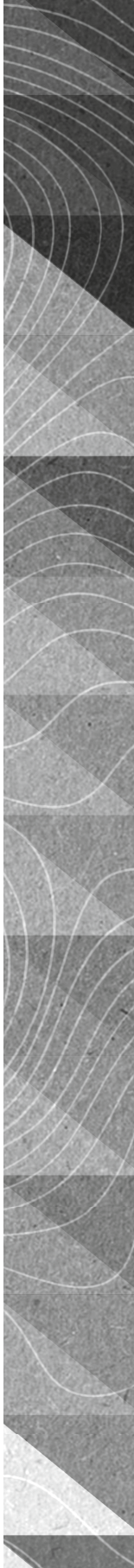
Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.

The first use of Dementia Care Mapping in the care for older people with intellectual disability: a process analysis according to the RE-AIM framework

Feija D. Schaap
Geke J. Dijkstra
Evelyn J. Finnema
Sijmen A. Reijneveld

Aging and Mental Health 2018;22:912-919

CHAPTER 5



Abstract

Background The aging of the population with intellectual disability (ID), with associated consequences as dementia, creates a need for evidence-based methods to support staff. Dementia Care Mapping (DCM) is perceived to be valuable in dementia care and promising in ID-care. The aim of this study was to evaluate the process of the first use of DCM in ID-care.

Methods DCM was used among older people with ID and care staff in twelve group homes of six organisations. We obtained data on the first use of DCM in ID-care via focus group discussions and face-to-face interviews with: care staff (N=24), managers (N=10) behavioural specialists (N=7), DCM-ID mappers (N=12), and DCM-trainers (N=2). We used the RE-AIM framework for a thematic process-analysis.

Results All available staff (94%) participated in DCM (*reach*). Regarding its *efficacy*, staff considered DCM valuable; it provided them new knowledge and skills. Participants intended to *adopt* DCM, by continuing and expanding its use in their organisations. DCM was *implemented* as intended, and strictly monitored and supported by DCM-trainers. As for *maintenance*, DCM was further tailored to ID-care and a version for individual ID-care settings was developed, both as standards for international use. To sustain the use of DCM in ID-care, a multidisciplinary, interorganisational learning network was established.

Conclusions DCM tailored to ID-care proved to be an appropriate and valuable method to support staff in their work with aging clients, and it allows for further implementation. This is a first step to obtain an evidence-based method in ID-care for older clients.

Introduction

The aging of the population with intellectual disability (ID), with associated consequences such as dementia, causes a need for evidence-based methods to support ID-care staff (from here: staff) in their work.^{1,2} Dementia has a large impact on the lives of people with ID, as well as of their relatives and housemates, and of the staff that provides long term and intensive support and care.³ Dementia is a relatively new phenomenon in ID-care, and staff often lacks knowledge and skills to address the behavioural changes and changing needs of their clients due to aging and/or dementia.⁴⁻⁷ Evidence-based methods to support staff are therefore needed but not yet available.

Dementia Care Mapping (DCM) is used internationally and is perceived as valuable in supporting staff in psychogeriatric nursing homes.⁸⁻¹³ Evidence on its effectiveness is mixed however.^{9,12-15} DCM has been shown to be feasible and promising in supporting ID-care staff in the United Kingdom and the Netherlands.¹⁶⁻¹⁹ DCM has been designed to improve the quality and effectiveness of care from the perspective of people with dementia.^{20,21} It is a person-centred, multi-component intervention, consisting of: (1) systematic observation, analysis and report, (2) feedback to the staff, and (3) action plans created by staff after reflection on their work, based on the observed needs of clients. DCM aims at improving care at different levels: individual (clients and care givers), group (care giving teams), multidisciplinary teams and management.^{14,22} Details are provided in Box 1 (p. 20). As a result of a previous pilot study we conducted on the feasibility of DCM in ID-care, DCM was tailored to ID-care in case histories and examples, without altering the core DCM-principles and DCM-codes.¹⁶

The aim of this study was to evaluate the process of use of DCM to ID-care practice. We gathered qualitative data from involved professional users of twelve group homes in the Netherlands. We used the RE-AIM framework to evaluate the first use of DCM in ID-care.²³ This framework has been shown to be a usable tool for evaluating the implementation of interventions. The results of this study can be used for developing an evidence-based method in ID-care for older clients.

Methods

Design

We set up a qualitative evaluation to gain insight into the first use of DCM in ID-care. We obtained detailed in-depth data from all professional users during focus group discussions, and during face-to-face interviews after the intervention, which consisted of two applications of the DCM cycle in twelve group homes. The data were analysed according to the principals of thematic analysis,^{24,25} and structured and reported using the RE-AIM framework.²³

Sample

We collected data from all professional users of DCM in ID-care practice. We provided DCM for vocational trained ID-care professionals who support people with ID living in group homes in all aspects of day-to-day life, including activities of daily living (ADL) and day care activities. In group homes, a small number (range 4 to 12) of people with ID in need of care, support, or supervision are living together. These group homes are part of larger organisations for people with ID of all ages and with various disabilities.

From each of the twelve participating group homes we included two staff members (N=24), all managers (N=10), behavioural specialists (N=7), DCM-ID mappers (N=12) and DCM-trainers (N=2). The participants attended focus group discussions or were interviewed face-to-face (Table 2). We conducted eight focus group discussions in total; four after the first cycle of DCM and four after the second. The participants in the focus group discussions were split by function category; staff from different group homes formed two groups, the managers and the behavioural scientists formed a group, and the mappers jointly formed a group. Participants who could not attend a focus group were interviewed face-to-face; these were four after the first cycle and two after the second cycle. The response rate to focus group discussions and interviews was 100%.

Ethical assessment

As DCM is an intervention aimed at staff, the Medical Ethical Committee of the University Medical Center Groningen considered that their approval was not required (decision M13.146536). All participants in this study gave their informed consent.

Intervention

The intervention consisted of two applications of a full cycle of DCM in twelve group homes for older people with ID (see Box 1; p. 20). The DCM-in-ID implementation protocol included a description of all preconditions before implementing DCM, and a description of every step for implementing DCM in ID-care.²⁶ In this protocol the preconditions and implementation steps on the level of mappers, the level of staff, and the level management are described. The protocol ascertained that DCM was implemented and applied similarly in each group home. It enabled a comparison of the group homes, even though these differed in (team) size, number of residents, culture and approach.

First, we trained from each of the twelve homes a staff member, to become a certified, advanced, dementia care mapper. The twelve selected staff members had the required competencies, such as experience with older people with ID, at least a bachelor's degree, and basic knowledge of person-centred care. Next, each mapper carried out DCM twice in the same group home, with an interval of seven months. Each mapper mapped a group home that was no part of the organisation to which he or she was affiliated, to avoid conflicts of interest. In each group home, four older clients were mapped simultaneously. After the mapping, the mapper presented the results in a report and in a feedback session to all available staff and the manager of mapping session the group home, whereupon staff wrote up action plans for better support of their clients. The action plans drawn up in the first DCM-cycle, were part of the second cycle, and were explicitly mentioned by the mapper in the feedback session. This provided staff the opportunity to reflect on their planned action in routine, daily care.

Procedure and measures

After each application of DCM, we obtained qualitative data on the first use of DCM in ID-care by professional users. We used focus group discussions, which is a specific method for gaining in-depth knowledge, on the experiences of staff, managers and behavioural specialists, ID-DCM mappers, and DCM-trainers were discussed. Those who could not participate in a focus group discussion were interviewed face-to-face; see Table 2.

The focus group discussions and interviews were semi-structured, led by a discussion leader [FDS, GJD or EJF] accompanied by an observer, and an interviewer [FDS, ASF], respectively. The discussions were structured using the empathy map, derived from the design

thinking-theory.²⁷ The empathy map facilitated tracing of the ‘pains and gains’ of the participants, allowing them to discuss what they ‘think and feel’, ‘say and do’, ‘hear’ and ‘see’ about the first use of DCM in ID-care. This provided in-depth information of the participants’ opinions and experiences on the use of DCM in ID-care.

Data analysis and reporting

The aim of this study was to evaluate the process of the first use of DCM to ID-care practice. We used the RE-AIM framework for a thematic analysis of the data on the implementation process.²⁵ The five themes of this framework (Reach, Effectiveness, Adoption, Implementation, Maintenance).²³ provide a basis for evaluating the implementation of social and health interventions,²⁸ and indicate key aspects in the implementation of psychosocial interventions.²⁹ We used the original definitions and underlying key questions of the RE-AIM model to measure its five key themes. We measured Reach as the proportion of staff that participated in all DCM activities during the study, i.e. involved in the introductory meeting, the feedback sessions and the action plan writing. Efficacy was measured as the perceived impact of DCM in daily care. We measured Adoption as the number of organizations willing to adopt DCM, and the intention of staff and managers to continue and extend the use of DCM in ID-care. With regard to Implementation, we measured fidelity to the DCM-in-ID protocol, including preconditions and consistency of the implementation. We measured Maintenance as the extent to, and how DCM was suitable in the long-term for ID-care. Table 1 shows the original definitions of the RE-AIM framework, as well as the operationalisations that we used in this study.

Table 1. Description of the definitions of the RE-AIM framework, way of measurement in this study and identified related (sub-)themes

Original definition	Definition of DCM in ID-study	Related (sub-)themes in DCM in ID-study
Reach The absolute number, proportion and representativeness of individuals who are willing to participate in a given intervention or program	Reach The proportion (%) of staff that participated in all DCM-activities (meetings and action plans) during the study.	No related themes, reach is measured as number
Efficacy The impact of an intervention on outcomes, including potential negative effects, quality of life and economic outcomes	Efficacy The perceived impact of DCM in the care for older people with ID.	Perceived use in practice Perceived impact (comparison to) Other methods
Adoption The absolute number, proportion, and representativeness of settings and the individuals within those settings who deliver the program and who are willing to initiate a program. Use of qualitative data to understand setting level adoption and staff participation	Adoption The number of organizations willing to adopt DCM. The intention of staff and managers to continue and extend the use of DCM in ID-care.	Demand for tools Expectations Ensuring implementation Support and commitment of staff and management Conditions for continuation
Implementation The fidelity to the program protocol and adaptations made to the intervention during the study. Costs of intervention in time and money. Consistency of the implementation across staff, time, setting and subgroups -focus is on process	Implementation The fidelity to the DCM-in-ID protocol, including preconditions. Consistency of implementation with focus on process.	Mappers' competences Basic and advanced training Support DCM in implementation Commitment of management Fulfilment of preconditions Re-organisations Experience of staff in person-centred care
Maintenance The extent to which a program becomes institutionalised or part of the routine of organisational practices and policies. If and how the program was adapted long-term	Maintenance The extent to, if and how DCM is adapted long-term to ID-care.	Continuation and further implementation Learning network Tailoring of DCM to ID-care Expansion to other target groups Individual mappings

We followed a stepwise procedure to analyse the data following the principles of thematic content analysis.^{24,25} First, we transcribed verbatim the contents of the focus group discussions and interviews. We used Atlas.ti computer software (version 7.5) for the analysis (Atlas.ti Scientific Software Development GmbH, Germany). Second, the first author [FDS] read and re-read all transcriptions and set up a concept code book with initial codes, and then discussed it with the second author [GJD]. Third, both authors [FDS, GJD] coded and compared transcripts. Based on this comparison we refined, relabelled and regrouped the codes until reaching consensus. Finally, after coding all transcripts, we divided the codes into definitions of the RE-AIM framework as shown in Table 1, and reported the results according to these themes.

The reports consisted of two parts. First, we described the characteristics of the sample. Next, we reported on the first use of DCM in ID-care using the definitions of the RE-AIM framework. The design, analysis and reporting of the focus group discussions and interviews were performed according to the COREQ-checklist: Consolidated Criteria for Reporting Qualitative Research.³⁰

Results

Characteristics of sample

In total, 57 professional users of DCM in ID-care participated in either a focus group discussion or a personal interview (Table 2). Of these, in both cycles 22 attended a focus group discussion or an interview, 18 in the first cycle and 17 in the second.

Table 2. Participants of the focus group discussions and interviews

	1st cycle		2nd cycle	
	FGD	IV	FGD	IV
Nr. of FDG/IV	4	4	4	3
Nr. of participants				
<i>Mappers</i>	12		9	3
<i>Staff</i>	14	2	13	3
<i>Managers</i>	5	5	7	
<i>Behavioural specialists</i>	2		5	
<i>DCM-trainers*</i>	2	2		

FGD: focus group discussions, IV: interview

** Both DCM-trainers participated each in a focus group discussion with mappers and with managers*

First use

In analysing the process of the first use of DCM in ID-care, the RE-AIM framework was used, and described where relevant. An overview of the (sub-)themes related to the five definitions of the RE-AIM framework is given in Table 1.

Reach

Almost all available staff (94%) participated in all DCM-activities (see Box 1; p. 20); those not participating were absent due to work shift or sickness. Facilitating to the reach was the content of the DCM-meetings. Staff, especially in group homes with few team meetings, appreciated the opportunity to share their knowledge and approaches. They reported that the DCM-meetings enabled them to discuss their individual clients, even as the group of clients, and the whys and wherefores of their daily practices.

Efficacy

Staff, behavioural scientists and managers all valued DCM highly in the care for older ID-clients. They found that it provided insights into how clients perceived care, and gave them concrete cues for providing tailored and more person-centred care. They valued the mappings and feedback by an independent mapper and found it to be insightful, the feedback made them aware of their own actions and their own behaviour to their clients. Evaluating care from the perspective of the client was new to them and improved their understanding of clients. For example: they understood better what could cause challenging behaviour in clients (with or without dementia), gained insight into the potential of easy-going clients whom they had underrated, and discovered in some clients irritations of which they had not been not aware. However, some staff members criticised that mappers did not provide concrete plans for individual clients; for they had expected more instant and ready-made solutions, although an inherent part of DCM is creating concrete plans by staff members themselves. A second criticism was that some mappers did not have in-depth knowledge of dementia, and could not add much knowledge for teams that had received previous training about older clients with ID and dementia.

Mappers, staff, behavioural scientists and managers mentioned the added value of DCM as a generic approach, whether or not for clients with dementia and/or behavioural problems.

They appreciated the cyclic and methodical character of DCM. They further mentioned that DCM helped them to apply the theoretical knowledge and other (person-centred) methods in which they previously had been trained; DCM gave this (theoretical) knowledge a practical dimension by means of concrete action plans. Finally, they expressed a demand for a complementary version of DCM with individual observations in private areas (such as the clients' own apartment) or during activities of daily living (ADL), because most challenges for staff to provide good care occur during ADL, for example while dressing the client.

Adoption

All participants intended to adopt and expand the use of DCM in their organisations. However, the ways they intended to adopt DCM differed. Options included were: once each half year for all clients, or upon request in case of behavioural problems, or for new clients in group homes. However, the integration of the ideas of DCM and person-centred care differed in the group homes. Although most participants reported being enthusiastic about DCM and mentioned that it met a need, actual compliance depended on the commitment of staff and managers, and on strong support and coordination by the manager, or a staff member with a leading role, in coordinating DCM. Because DCM was applied by means of this study, the compliance to the procedures and plans were not yet fully integrated into regular care routines in each group home. Some managers, mappers and DCM-trainers mentioned that full integration of the routines and ideas of DCM and person-centred care takes more time and experience. In addition, adoption of DCM in the participating group homes, as the managers mentioned, depends on the financial resources of the organisations and thus on decisions by the management board.

Implementation

The implementation of DCM in the group homes was in accordance with the DCM-in-ID protocol, and the fidelity to the protocol was strictly monitored and supported by DCM-trainers. This step-by-step protocol was followed, but despite it turned out that the group homes could not fulfil all required preconditions for optimal implementation of DCM,²⁶ such as mappers' skills, safe and stable teams, and provision of enough time and resources.

Regarding performance quality, i.e. the mappers' skills, after finishing the basic and advanced mappers training, the newly trained mappers felt they were not fully capable of

carrying out DCM on their own. Therefore, strong support was needed for implementation; DCM mappers needed counselling and close cooperation with the DCM-trainers. The mappers reported various reasons for needing such support: first, all mappers found the training informative, but due to wide variation in their educational levels, the training did not fit all mappers. Second, mappers and trainers expressed that advanced training followed basic training too quickly (within four months), without allowing enough time for practical experience in between. Third, not all mappers had the required competences, such as planning, drawing up reports, providing feedback, and implementation skills. Fourth, in practice the mappers found the training and implementation of DCM more time-consuming than they had expected. Carrying out DCM: being present during the introductory meeting, observing (mapping), drawing up a report, and providing feedback, took more time than calculated. Finally, the mappers reported that carrying out DCM was not possible within their regular jobs; moreover, not all mappers were partially exempt from their daily jobs while applying DCM.

As for the staff and managers, the success of DCM was dependent on their commitment, their organisation of care, and their underlying visions. First mentioned was the openness and commitment of the teams to DCM, such as willingness to reflect on their own actions and work. For example, the instability and insecurity of some teams, due to reorganisations in management and savings in budget, resulted in less openness to the feedback of DCM and less commitment on the part of staff and managers. Second, the amount of experience of applying person-centred care was mentioned as an important factor. Some teams were already trained in the use of a person-centred approach (i.e. method Urlings³¹), and reported that DCM helped them to understand and apply this approach in practice. Third, staff mentioned that the action plans were concrete and were discussed very often during work time, especially in work meetings, although managers sometimes had to pay extra attention to them. Nevertheless, some staff reported that their own action plans were not always put into practice due to a high workload, as well as to difficulties in translating and fitting their actions and reports into the registration systems. However, in two group homes with a registration system focused on goal attainment, the actions carried over into practice, both with the individual clients as with the client group altogether. Lastly, managers of some group homes perceived the implementation protocol of DCM as too hierarchical. They found it unnecessary to focus mainly on management, with meetings organised only for managers and

emphasis on their allotted coordinating role. They suggested a more bottom-up approach, including staff in the implementation and coordinating process, and thereby gaining more commitment by the teams.

Maintenance

All participating organisations expressed the wish to continue the use of DCM, although the steps differ per organisation. One organisation (a) will implement DCM in a new centre of knowledge for older people with ID. Another organisation (b) will train staff and behavioural scientists to become advanced DCM-ID mappers in their organisations. Three organisations (c,d,e) drew up an implementation plan. In another organisation (f), two advanced mappers applied the training for DCM in individual ID-care settings and used both versions (i.e. the 'regular' and the individual version) complementary to each other through their organisation, for people with or without dementia.

Although maintenance of the intervention was not yet guaranteed in the participating organisations, respondents gave a number of suggestions for further and optimal use of DCM-in-ID. These were for example: more attention for dementia and person-centred care in the mappers' training, tailoring the case histories in the DCM-in-ID manual and mappers' training to ID-care, and using DCM in individual situations in private areas and during ADL in ID-care.

To support a sustainable application of DCM in ID-care, a multidisciplinary, inter-organisational learning network was established to support and empower DCM-ID mappers in the use and implementation of DCM in their organisations. This learning network had two main purposes: first, increasing the mappers' skills by face-to-face exchange of their mutual knowledge, and second, empowering the mappers to stimulate implementation by using a bottom-up approach in their organisations. This learning network consists of a bi-monthly meeting, wherein the participants introduce their own issues. The meetings and their contents are prepared by the participants, supported by two teachers.

Discussion

With this qualitative study we have described the first use of DCM in ID-care. Regarding the use of DCM in ID-care practice, the professional users rated DCM positively regarding its reach, efficacy, adoption, implementation, and maintenance. All participants agreed that DCM as

supplementary method added to the psychosocial approaches that they currently used in daily practice. First, DCM provided them new skills and knowledge in caring for older people with ID and dementia, and made them respond better to the needs of their clients. In our study this was reflected in the high reach (94%), the high perceived efficacy, and the high willingness to adopt DCM in routine care practice. The need for a method is widely reported in studies of staff working with older people with ID; the increasing age and accompanying implications (like dementia) of clients requires a method to support staff in their work.^{1,5,16,32-36} That DCM meets this need is reflected in our study in the considered efficacy and the willingness to adopt DCM in regular practice.

Furthermore, we found that participants were positive about the insights that DCM gave as to how clients, whether or not with dementia, perceived care, and about the concrete cues for providing tailored and more person-centred care. The principles of person-centred care are new, yet increasingly used in ID-care.^{37,38} Our study showed that even though staff are often trained in (person-centred) methods or visions, the application of this in practice remains difficult. DCM with its cyclic, methodical character, turned out to be helpful in understanding, translating and applying the principles of these methods and visions. Moreover, we found that in group homes with staff experienced in person-centred care, DCM was more successful.

The reported challenges concerned the implementation of DCM in practice and its further implementation through the organisations. This confirms findings of Van de Ven (2014) and Quasdorf et al. (2017) in their studies on the implementation of DCM for people with dementia (without ID).^{39,40} We found the DCM-in-ID implementation protocol helpful for implementing DCM in the twelve group homes with varying cultures, team characteristics, and habits in care, even though the protocol needs some further tailoring to ID-care. Moreover, our study showed, that fulfilling all preconditions in practice is difficult and is dependent indeed on the culture, team characteristics, and care habits of each group home. The success of implementation was dependent on the commitment of staff and managers and the presence of a staff member or manager with a leading role. Previous research of DCM concluded that to reach optimal results, the implementation and fulfilling of preconditions (such as commitment and a person-centred care compliant vision) require strong and accurate attention.^{10,15-17,40-43} Adequate realisation of the preconditions should be considered before

implementing DCM, to avoid the Type III error for undermining the credibility of an intervention by a poor delivery.⁴⁴⁻⁴⁶

The tailoring of DCM to ID-care was an iterative process. We assessed in this study a version of DCM that had been tailored to ID-care, based on the results of a piloting of DCM we conducted previously to examine the feasibility of DCM in ID-care. This previous tailoring of DCM to ID-care concerned purely case histories and examples, without changing the original principals and codes of DCM. The results of this RE-AIM based assessment will be used for a further similar tailoring of DCM to ID-care. The discussion and refining after each use is a proven method for attuning interventions to the target group,^{47,48} as long the adaptations are made based on substantial evidence and do not compromise the core elements of the intervention.⁴⁹ The tailoring of the mappers' training, such as more attention to knowledge of dementia and person-centred care, strengthened the core elements of DCM for ID-care. The tailoring of the manual, codes, and case histories have been justified by the daily practices of ID-care.

Furthermore, to establish a multidisciplinary, interorganisational learning network to support and empower DCM-ID mappers in the use and sustainable implementation of DCM in their organisations a more bottom-up approach was added.⁵⁰

Strengths and limitations

A key strength of this study was our use of a multi-informant design to examine the first use of DCM in ID-care settings. The results from the different perspectives of all participating group homes turned out to be complementary and did not conflict. Moreover, we examined the first use of DCM in practice in twelve different group homes of six different organisations for people with ID, each with its own vision, culture, team characteristics, and habits in care; this enhances the validity of our results for routine ID-care practice. Our findings are thus likely to represent a wide range of ID-care.

A limitation of this study is that we fully rely on qualitative reports. These may be biased due to, for instance, the additional attention to professionals as part of the study, and do not yield a full quantification of the implementation process. This evidently deserves further study.

Implications

This study showed that, due to a lack of evidence-based methods in ID-care and the strong demand for cues for putting theoretical knowledge into practice, DCM fulfils a strong demand and is perceived to be valuable and usable in the care of older people with ID. Therefore, the tailored version of DCM for ID-care, allows for wider implementation in the care for these older people.

The implementation of DCM in ID-care required strong attention. We recommend the use of a further tailored DCM-in-ID protocol as it seem to allow flexibility to fit in various situations. Further, we recommend considering to split the implementation of DCM into two parts: a part aimed at (higher) management and a part aimed at practice. Next, the required DCM preconditions for successful implementation in ID-care should be reconsidered. For example: for optimal compliance to the mappings and the feedback in ID-care, DCM should be carried out by an ID-care behavioural specialist. Next, further tailoring of the mappers training to ID-care, such as paying more attention to knowledge on dementia, will strengthen the core elements of DCM. Furthermore, as the combination of DCM with person-centred care appeared to be successful, a broader (theoretical) knowledge on the part of staff in person-centred care should be considered.

The outcomes of this RE-AIM based assessment of the implementation led to a further tailoring in the DCM-manual, implementation protocol and mappers training for DCM-in-ID. For example, more attention on dementia was provided in the training for DCM-in-ID mappers, to increase their knowledge of dementia. Second, to increase the knowledge and competence of mappers and staff in providing person-centred care in ID-settings, an e-learning module of person-centred care was added to the basic mappers' training and made optionally available to staff. Next, the design of the advanced DCM-training was changed; the content of the training was divided into modules, allowing mappers to choose which skills they needed to improve in order to become independent DCM-mappers in ID-care. Moreover, based on the experiences in this study, a training in DCM in individual ID-care settings was developed, based on the DCM version for individual settings used in Dutch home-care situations for people with dementia (DCM-OT).⁵¹ Finally, one DCM-ID mapper was being educated to be deployed as a DCM-ID trainer, and will in turn be able to train new staff to become (advanced) mappers.

Finally, the effects and further use of the fully tailored version of DCM to ID-care should be evaluated, also with quantitative measures. This could include a cost-analysis and the evaluation of the adapted version for individual observations in private areas. Such further assessment may help to come to an evidence-based method for older people with ID.

Conclusion

With this qualitative study we have described the process of the first use of DCM in ID-care for older people. All professional users rated the use of DCM-in-ID positively regarding its reach, efficacy, adoption, implementation, and maintenance. DCM-in-ID meets a need for a supplementary method regarding aging ID-clients, and adds to the currently used psychosocial approaches in daily practice, and thus allows for further development and wider implementation in ID-care. The DCM-implementation protocol provided sufficient guidance to avoid implementation errors, but the protocol should be further tailored to ID-care and should be adhered to more closely, especially regarding meeting the required preconditions. This study is a first step to obtain an evidence-based method of ID-care for older clients, whether or not with dementia, and allows further research to assess the effectiveness.

References

1. Cleary J, Doodey O. Nurses experience of caring for people with intellectual disability and dementia. *Journal of Clinical Nursing*. 2017; 26(5-6), 620-631.
2. Duggan L, Lewis M, Morgan J. Behavioural changes in people with learning disability and dementia: A descriptive study. *Journal of Intellectual Disability Research*. 1996;40(4):311-321.
3. Janicki MP, Keller SM, eds. *My thinker's not working': A national strategy for enabling adults with intellectual disabilities affected by dementia to remain in their community and receive quality supports*. Hamden, Connecticut: National Task Group on Intellectual Disabilities and Dementia Practice; 2012.
4. Janicki MP. Quality outcomes in group home dementia care for adults with intellectual disabilities. *Journal of Intellectual Disability Research*. 2011;55(8):763-776.
5. Iacono T, Bigby C, Carling-Jenkins R, Torr J. Taking each day as it comes: Staff experiences of supporting people with Down syndrome and Alzheimer's disease in group homes. *Journal of Intellectual Disability Research*. 2014;58(6):521-533.
6. Emerson E. *Challenging behaviour : Analysis and intervention in people with severe learning disabilities*. Cambridge: Cambridge University Press; 2001.
7. Myrbakk E, von Tetzchner S. Psychiatric disorders and behavior problems in people with intellectual disability. *Research in Developmental Disabilities: A Multidisciplinary Journal*. 2008;29(4):316-332.
8. Kuiper D, Dijkstra GJ, Tuinstra J, Groothoff JW. The influence of dementia care mapping (DCM) on behavioural problems of persons with dementia and the job satisfaction of caregivers: A pilot study. *Tijdschrift voor Gerontologie en Geriatrie*. 2009;40(3):102-112.
9. Chenoweth L, King MT, Jeon YH, et al. Caring for aged dementia care resident study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: A cluster-randomised trial. *The Lancet Neurology*. 2009;8(4):317-325.
10. Jeon YH, Luscombe G, Chenoweth JL, et al. Staff outcomes from the caring for aged dementia care REsident study (CADRES): A cluster randomised trial. *International Journal of Nursing Studies*. 2012;49(5):508-518.
11. Van de Ven G. *Effectiveness and costs of dementia care mapping intervention in Dutch nursing homes (dissertation)*. Nijmegen, the Netherlands: Radboud Universiteit Nijmegen; 2014.
12. Rokstad AMM, Røsvik J, Kirkevold Ø, Selbaek G, Saltyte Benth J, Engedal K. The effect of person-centred dementia care to prevent agitation and other neuropsychiatric symptoms and enhance quality of life in nursing home patients: A 10-month randomized controlled trial. *Dementia & Geriatric Cognitive Disorders*. 2013;36(5):340-353.
13. Barbosa A, Lord K, Blighe A, Mountain G. Dementia care mapping in long-term care settings: A systematic review of the evidence. *International Psychogeriatrics*. 2017;29(10):1609-1618.
14. Van de Ven G, Draskovic I, Adang EMM, et al. Effects of dementia-care mapping on residents and staff of care homes: A pragmatic cluster-randomised controlled trial. *PLoS ONE*. 2013;8(7):1-7.
15. Dichter MN, Quasdorf T, Schwab C, et al. Dementia care mapping: Effects on residents' quality of life and challenging behavior in german nursing homes. A quasi-experimental trial. *International Psychogeriatrics*. 2015;27(11):1875-92.
16. Schaap FD, Fokkens AS, Dijkstra GJ, Reijneveld SA, Finnema EJ. Dementia care mapping to support staff in the care for people with intellectual disabilities and dementia: A feasibility study. *Journal of Applied Research in Intellectual Disabilities*. 2018;31(6):1071-1082.
17. Jaycock S, Persaud M, Johnson R. The effectiveness of dementia care mapping in intellectual disability residential services. *Journal of Intellectual Disabilities*. 2006;10(4):365-375.
18. Persaud M, Jaycock S. Evaluating care delivery: The application of dementia care mapping in learning disability residential services. *Journal of Learning Disabilities*. 2001;5(4):345-352.
19. Finnamore T, Lord S. The use of dementia care mapping in people with a learning disability and dementia. *Journal of Intellectual Disabilities*. 2007;11(2):157-165.

20. Kitwood T. Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*. 1992;12:269-87.
21. Brooker D, Surr CA. *Dementia care mapping. Principles and practice* (Dutch version). Bradford: Bradford Dementia Group; 2005.
22. Brooker D, Latham I. *Person-centred dementia care: Making services better with the VIPS framework*. London: Jessica Kingsley Publishers; 2015.
23. Glasgow RE. Evaluating the public health impact of health promotion interventions: The RE-AIM framework. *American Journal of Public Health*. 1999;89(9):1322-7.
24. Guest G, MacQueen KM, Namey EE. *Applied thematic analysis*. Thousand Oaks, California: SAGE Publications; 2011.
25. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology*. 2006;3(2):77-101.
26. Bradford Dementia Group. *Implementation of dementia care mapping. Handbook for implementation of DCM in organisations (Dutch version)*. Bradford: University of Bradford; 2014.
27. Curedale R. *Design thinking: Process and methods manual*. Topanga, California: Design Community College Incorporated; 2013.
28. Gaglio B, Shoup JA, Glasgow RE. The RE-AIM framework: A systematic review of use over time. *American Journal of Public Health*. 2013;103(6):e38-e46.
29. Boersma P, Van Weert J, Lakerveld J, Dröes R. The art of successful implementation of psychosocial interventions in residential dementia care: A systematic review of the literature based on the RE-AIM framework. *International Psychogeriatrics*. 2015;27(1):19-35.
30. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Journal of the International Society for Quality in Health Care*. 2007;19(6):349-357.
31. Urlings H. Urlings method. In: Twint B, de Bruin J, eds. *Handbook intellectual disability: 24 succesful methods (in Dutch: Handboek verstandelijke beperking: 24 succesvolle methoden)*. Amsterdam: Boom Cure & Care; 2014:293.
32. Wilkinson H, Kerr D, Cunningham C. Equipping staff to support people with an intellectual disability and dementia in care home settings. *Dementia*. 2005;4(3):387-400.
33. Furniss KA, Loverseed A, Lippold T, Dodd K. The views of people who care for adults with Down's syndrome and dementia: A service evaluation. *British Journal of Learning Disabilities*. 2012;40(4):318.
34. McCarron M, McCallion P, Fahey-McCarthy E, Connaire K, Dunn-Lane J. Supporting persons with Down syndrome and advanced dementia: Challenges and care concerns. *Dementia*. 2010;9(2):285-298.
35. Perera BD, Standen PJ. Exploring coping strategies of carers looking after people with intellectual disabilities and dementia. *Advances in Mental Health and Intellectual Disabilities*. 2014;8(5):292-301.
36. Watchman K. Supporting people with Down's syndrome and dementia. *Learning Disability Practice*. 2014;17(9):33-41.
37. Ratti V, Hassiotis A, Crabtree J, Deb S, Gallagher P, Unwin G. The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review. *Research in Developmental Disabilities*. 2016;57:63-84.
38. Doody O. VIP care in learning disability nursing: Owen doody discusses elements of care that are central to learning disability nurses' work with clients who have recently transferred to community based-care. *Learning Disability Practice*. 2016;19(4):29-33.
39. Van de Ven G, Draskovic I, Brouwer F, et al. Dementia care mapping in nursing homes: A process analysis. In: Van de Ven G, ed. *Effectiveness and costs of dementia care mapping intervention in Dutch nursing homes (dissertation)*. Nijmegen, the Netherlands: Radboud University Nijmegen; 2014.
40. Quasdorf T, Riesner C, Dichter MN, Dortmann O, Bartholomeyczik S, Halek M. Implementing dementia care mapping to develop person-centred care: Results of a process evaluation within the Leben-QD II trial. *Journal of Clinical Nursing*. 2017;26(5-6):751-765.

41. Chenoweth L, Jeon YH, Stein-Parbury J, et al. PerCEN trial participant perspectives on the implementation and outcomes of person-centered dementia care and environments. *International Psychogeriatrics*. 2015;27(12):2045-57.
42. Brownie S, Nancarrow S. Effects of person-centered care on residents and staff in aged-care facilities: A systematic review. *Clinical Interventions in Aging*. 2013;8:1-10.
43. Rokstad AMM, Vatne S, Engedal K, Selbæk G. The role of leadership in the implementation of person-centred care using dementia care mapping: A study in three nursing homes. *Journal of Nursing Management*. 2015;23(1):15-26.
44. Moniz-Cook E, Elston C, Gardiner E, et al. Can training community mental health nurses to support family carers reduce behavioural problems in dementia? an exploratory pragmatic randomised controlled trial. *International Journal of Geriatric Psychiatry*. 2008;23(2):185-191.
45. Hulscher M, Laurant M, Grol R. Theories on implementation of change in healthcare. In R. Grol, M. Wensing, & M. Eccles (Eds.), *Improving patient care: The implementation of change in clinical practice* (pp. 256–272). London: Elsevier. 2005.
46. Vernooij-Dassen M, Moniz-Cook E. Raising the standard of applied dementia care research: Addressing the implementation error. *Aging & Mental Health*. 2014;18(7):809–814.
47. Boots LM, de Vugt ME, Withagen HE, Kempen GI, Verhey FR. Development and initial evaluation of the web-based self-management program “partner in balance” for family caregivers of people with early stage dementia: An exploratory mixed-methods study. *JMIR research protocols*. 2016;5(1):e33.
48. Waugh A, Austin A, Manthorpe J, et al. Designing a complex intervention for dementia case management in primary care. *BMC family practice*. 2013;14(1):101.
49. Tabak RG, Khoong EC, Chambers DA, Brownson RC. Bridging research and practice: Models for dissemination and implementation research. *American Journal of Preventive Medicine*. 2012;43(3):337-350.
50. Wenger E. *Communities of practice: Learning, meaning, and identity*. Cambridge: Cambridge University Press. 1998.
51. Visser, A, Dijkstra, GJ, Post, A, & Haakma, F. *The acceptability and practicality of dementia care mapping on persons with dementia in home-care situations (in Dutch)*. Groningen: Applied Health Research, University, Medical Center Groningen, University of Groningen. 2012

